



Supporting and Advocating for HIV-positive Health Care Workers

BENJAMIN SCHATZ, JD*

The issue of AIDS (acquired immunodeficiency syndrome) has largely disappeared from public debate. The problems facing the nation's 50,000 to 70,000 human immunodeficiency virus (HIV)-positive health care workers have not disappeared, however; indeed, when the lamentable history of this society's handling of AIDS is finally written, I believe that the United States' cruel, unscientific scapegoating of HIV-positive health care workers and the willingness—indeed, the eagerness—of many in the mainstream medical community to sacrifice their HIV-infected colleagues to protect themselves from a fearful public, will stand out as one of the most destructive and inexcusable chapters. The continued widespread silence about this tragedy perpetuates it. This paper attempts to help break that silence.

In November 1990, I was hired by the American Association of Physicians for Human Rights—which recently changed its name to the Gay and Lesbian Medical Association (GLMA)—to create and direct the Medical Expertise Retention Program (MERP). Since its inception, MERP has assisted more than 1,200 health care workers who are HIV-positive, who suspect they are HIV-positive, or who have recently experienced needle sticks. We provide a broad range of services, including assistance and referrals, support groups and other opportunities for networking, policy updates, job counseling, psychiatric referrals, extensive advocacy, and public education. Sometimes, we simply provide a supportive ear.

* Benjamin Schatz is Executive Director, Gay and Lesbian Medical Association, 273 Church St, San Francisco, CA 94114.

Because MERP is sponsored by a medical organization, approximately 79% of our clients have been physicians or medical students. An additional 9% are nurses, 6% are dentists, and 5% are in other health professions, including physician assistants, medical technicians, researchers, acupuncturists, dental students, nursing students, paramedics, physical therapists, surgical assistants, phlebotomists, occupational therapists, x-ray technicians, dialysis technicians, midwives, and others. Clients are from 37 states, two Canadian provinces, and several other nations. Although GLMA is a gay and lesbian organization, MERP serves heterosexual or bisexual clients as well as those who are gay or lesbian. It serves all persons infected through homosexual sex, heterosexual sex, occupational exposure, hemophilia, and intravenous drug use.

Historical Overview

In 1990, the US Centers for Disease Control and Prevention (CDC) reported that Kimberly Bergalis, a patient of Florida dentist David Acer, apparently had become infected with HIV in a dental setting through a mechanism that the CDC was, and remains, unable to identify. In January 1991, the CDC indicated that several other of Dr. Acer's patients—the total eventually reached six—had become inexplicably infected. The incident generated massive public fear and inflammatory media attention. The American Medical Association and American Dental Association both hastily drafted public statements declaring that HIV-infected health care providers have an "ethical obligation" to refrain from performing invasive procedures.

The vast majority of experts and organizations testifying before the CDC at a special meeting the following month, however, urged the CDC not to restrict HIV-positive health care workers. They pointed out that the risk presented by HIV-infected providers to patients is theoretical and extremely remote; that the best way to prevent transmission in the health care setting is to require universal infection-control procedures by all health care providers; and that restricting thousands of infected health care workers

would be enormously expensive and destructive to the well-being of millions of Americans who rely on them for health services. Some challenged whether Dr. Acer's patients had actually been infected in the dental setting. Others conceded the likelihood of the linkage but asserted that poor dental infection-control practices, rather than Dr. Acer's HIV status, were to blame. Many others insisted that it would be inappropriate to formulate broad national policy on the basis of one extraordinary, inexplicable, and unreplicated case.

The CDC itself has conceded that the risk of becoming HIV-infected via blood-to-blood transmission from an HIV-positive surgeon or dentist is less than the risk of being killed by a tornado or in a plane crash. Nonetheless, in July 1991, the CDC issued guidelines urging all health care workers who perform "exposure-prone" procedures to be tested for HIV, and, if they are positive, to "voluntarily refrain" from performing those procedures unless approved by an "expert review panel." A few hours before the guidelines were to be released, a new and ominous provision was inserted at the behest of Senator Orrin Hatch (R-Utah). Over the scientific objections of CDC officials, the guidelines were amended to urge infected providers who perform "exposure-prone" procedures—even those given a green light by a review panel—to notify patients of their status. In practical terms, of course, this would mean abandoning their professions.

In addition to the problems created by the Hatch provision, the CDC guidelines posed another dilemma: they did not provide clear guidance about what the term "exposure-prone" meant, creating a hodgepodge of confusion and inconsistency. In response, the CDC promised to develop a process through which medical and dental societies would develop a list of procedures that are exposure-prone.

Meanwhile, the US Congress, at the behest of Senator Jesse Helms (R-NC), passed a law in October 1991 requiring all states to adopt guidelines "equivalent" to those of the CDC. The CDC subsequently announced that the states would be allowed great latitude in determining "equivalence," and a broad range of guide-

lines have since been promulgated. Most are more lenient than those of the CDC, but to date, all have been CDC-certified as equivalent.

The CDC did not, however, succeed in its efforts to devise a list of exposure-prone procedures. Virtually without exception, medical and dental societies refused to participate in what they considered a sham process, declaring that there is no scientific basis for restricting infected providers per se from performing any procedures at all. In response to mounting criticism from the medical and scientific communities, the CDC instead developed and widely circulated draft guidelines in the spring of 1992. These draft guidelines would have rescinded the Hatch patient-notification provision and declared that restrictions against infected health care workers are justified only if the worker poses a significant risk of infecting patients, based on an assessment of his or her individual technique, skill, experience, and compliance with infection-control procedures.

Unfortunately, these new guidelines were vetoed by high-level officials of the Bush Administration at the US Department of Health and Human Services (HHS) for reasons that were not publicly announced. Thus, the original CDC guidelines—which restrict people who perform procedures that the CDC cannot define and which have been discredited by medical societies and by the CDC itself—remain in place and are part of federal law.

The Situation Today

Not surprisingly, infected health care workers—particularly surgeons and dentists—find themselves in a quandary. It has been nearly 5 years since the Kimberly Bergalis controversy, and no similar cases have emerged. Look-back studies involving 19,000 patients have failed to detect even a single patient who has contracted the virus from an infected provider,¹ confirming again the infinitesimal level of risk involved. Most state health department guidelines contradict those of the CDC, with the majority taking the position that HIV infection alone does not justify

restricting any health care worker's professional duties, regardless of the procedures performed. Some states, however, do impose a variety of notification or restriction requirements. Further complicating the situation, state medical or other licensing boards may impose their own, differing requirements, although few require HIV-infected physicians to self-report at this time.²

It is the courts, however, that have most complicated and confused the situation. Relying in part on the CDC's patient-notification provisions, the courts in two states have upheld the right of patients to sue infected surgeons for "emotional distress" for not disclosing their HIV status—even though the patients remain uninfected.³ A third court has reached a different conclusion,⁴ requiring actual exposure to HIV for a patient to have a valid legal claim. The courts also have been divided about discrimination claims filed by infected providers who have lost their jobs. A federal judge recently struck down most of the claims of a surgeon who sued a Philadelphia hospital under the Americans with Disabilities Act for terminating his privileges after he followed the CDC's guidance and voluntarily disclosed his HIV status to hospital administrators.⁵ In another case, however, an infected pharmacist (who, admittedly, does not perform invasive procedures) was successful in his bid to remove restrictions placed on him by his hospital employer.⁶

In the ensuing confusion, MERP has received numerous calls from panicked health care workers. An emergency-room physician contacted us after being asked his HIV status by his malpractice insurer. After indicating that he was infected, his coverage was dropped, and he was forced to quit practicing. We have been contacted by family practice, psychiatric, and ophthalmology residents who were dismissed on the advice of hospital lawyers and by nurses and operating-room technicians who were involuntarily transferred to nonpatient care activities at reduced salaries. We have heard from young pediatricians and family practitioners who were forced out of their practices at fire-sale prices after their partners learned their HIV status. In those instances, the physi-

cians were left with medical education and training debts approaching \$100,000.

Issues of confidentiality have been particularly problematic for infected providers. A dentist called us after losing his license when his doctor reported his status to his state dental board. One internist lost his job after personnel at a hospital 70 miles from his home leaked the news that he had been hospitalized for an HIV-related condition. A distraught physician contacted us after seeking counseling from a therapist when he learned he was HIV-positive. The therapist told the doctor that he would no longer see him and threatened to report him to state officials.

I should emphasize that it is not only those who are HIV-positive who experience discrimination. We have received many calls from numerous physicians, nurses, technicians, and other gay men who have been told that they need to test HIV-negative to obtain or keep a job. In one instance, a state licensing board received an anonymous tip that a physician was HIV-positive and gave him one day to gather all his medical records and to describe the procedures he had performed at every facility in which he had worked over the past 10 years.

The examples presented here represent just a small fraction of the 1,200 phone calls for assistance we have received at our office; the problems reported to us undoubtedly represent only a fraction of those that are actually occurring. It is hardly surprising, therefore, that many health care workers feel frightened and besieged. One of my clients routinely drives 100 miles to buy his AZT with cash. I have received several calls from infected providers who have been afraid to reveal their HIV status to anyone but me. In many cases, infected providers are desperate to talk to others in the same situation but are too fearful to give me a name or a telephone number so that I can make a connection for them.

Why don't more people know about all of the discrimination that is taking place? The answer, of course, is that discrimination makes it virtually impossible for those who have been victimized to speak out or to seek redress. Time and time again, our clients tell us that if they protest discrimination, their HIV status will

become public, and they will be sued. Because this scenario has been repeated with several of MERP's clients, such fears must be considered reasonable. As a result, infected providers are victimized, and suffer, in silence.

The Needs of Infected Providers

From the calls and letters MERP has received, it is possible to draw some conclusions. First, most infected providers, like most people with HIV, are young. In a survey of 200 HIV-positive and "high-risk" untested providers,⁷ 65% were in their twenties or thirties. Not surprisingly, many of these people—54% in our survey—also have substantial debt for their professional training. Forty percent of those reporting debt indicated that their professional training debts exceed \$50,000. Many infected health care workers are in no financial position to retire; their precarious situation is worsened because they often are unable to obtain disability insurance.

The fear among infected providers is widespread and palpable. Seventy-three percent of the infected providers responding to our survey—including a majority of those who perform no invasive procedures—indicated that they feared losing their job or practice because of their HIV status. Fifty-eight percent avoided seeking HIV treatment or submitting HIV-related health insurance claims through their job's health plan because of concerns about confidentiality. Among high-risk providers who had not yet taken the HIV test, 57% reported that the specter of forced restrictions made them less likely to be tested; only 7% indicated that they were more likely to be tested as a result.

Infected health care workers need a broad range of services. A majority (52%) of those calling our office between the summer of 1992 and the summer of 1994 sought legal assistance or referral. One third (32%) sought a support network of infected providers. Far more seek professional counseling and advice about how to stay in medicine (25%) than advice about leaving medicine or selling their practices (8%). Significant numbers also have sought

information about state or federal guidelines or licensing requirements (13%), psychiatric/psychologic referrals (5%), or emotional support (19%). Approximately 6% of our callers had concerns about needlesticks or other occupational health issues.

Perhaps the service that infected providers most need is advocacy to improve the horrendous situation they confront. Indeed, the two services ranked most highly by survey respondents were "fighting repressive legislation and licensing requirements" and "efforts to convince employers and malpractice and disability insurers not to discriminate." More than 90% of respondents described such services as "highly" or "extremely" valuable.

For the present, the best we can do for many of our clients is to help them navigate stormy waters; we cannot make the storms go away. We cannot single-handedly change outmoded CDC guidelines or overturn hysteria-based court decisions. Nor can we create an easy mechanism to retrain large numbers of infected surgeons and dentists; most meaningful training would require years of schooling, often with grueling schedules that are far from ideal for immune-compromised individuals.

The irony, of course, is that the price of all the confusion and injustice is being paid not only by HIV-positive health care workers but by society as a whole. Increasing numbers of patients are being denied the invaluable services of qualified health care professionals. Society has been deprived of its investment in the education and training of these workers, the shortage of medical personnel in inner cities and underserved rural areas is worsening, and the stigma associated with HIV infection has intensified. In addition, legal protections for workers with many other medical conditions and disabilities are being compromised, because HIV-positive employees are dismissed on the basis of a remote and speculative risk.

There are other negative societal ramifications as well, particularly with respect to broader AIDS policy issues. As uninfected providers become more aware of the professional price that must be paid if they become occupationally infected, their incentive to deny care to infected patients has increased and their incentive to

report needlesticks to employers has decreased. The public spectacle of a major CDC AIDS policy initiative being condemned as scientifically unjustifiable by virtually all medical and public health groups that have taken a stance on the issue, has undercut the CDC's credibility. That, in turn, impedes the CDC's ability to gain the trust of, or to work with, either the public or the public health community. The resources wasted on this issue by government health agencies are particularly troublesome given the extent of pressing HIV-related needs that remain inadequately addressed. In the wake of the massive resurgence of new HIV infections among gay and bisexual men, still largely overlooked by many public health authorities, it is a tragic misplacement of priorities to devote countless hours of government "HIV prevention" activity to an epidemiologic non-issue.

What, then, do we do? The most important thing is to break the silence. We cannot give up on this issue. We must keep the pressure on the CDC to bring its guidelines into the mainstream of scientific thinking. The fact that a policy that the CDC itself has admitted lacks credibility has been allowed to remain in place for nearly three years, should be an embarrassment to everyone at the CDC, the Department of Health and Human Services, and the Clinton Administration.

I urge readers to remind the CDC that, in light of a 1992 study showing that 80,000 US patients die every year from infections they acquire when hospitalized, often because providers fail to wash their hands,⁸ and in light of a 1991 study revealing that one in three medical residents, exhausted from shifts of up to 36 hours, admits to inadvertently contributing to a patient's death,⁹ there are more important health care risks on which to focus national attention. I ask you to prod your medical society, nursing association, AIDS organization, hospital, and/or company to speak out on this issue, to sponsor public discussion about the problem, and to keep up the pressure. The medical and other health organizations that were silent and acquiescent when their voices were most needed, bear a particular responsibility to help redress a wrong created in part through their complicity.

It also is important to spread the word about MERP to HIV-positive health care workers. Our program is on their side, and we stand ready to help in whatever way we can. GLMA offers two publications that may assist victims of discrimination: (a) *The Legal Rights and Obligations of HIV-Infected Health Care Workers*, available for \$10, and (b) "May God and the Community Help Us All," the results of a survey of nearly 200 HIV-positive and "high-risk" untested health care workers, available for \$7. Tax-deductible contributions to GLMA are welcome.

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